

Adaptation and coping of people who underwent brain tumor surgery: literature review

Meza-García, Carlos Francisco^{1*}; Reynaga-Ornelas, Luxana²; Moreno-Pérez, Norma Elvira³

ABSTRACT

Introduction: The return of people to everyday life after brain tumor surgery impacts their biological, social, psychological, environmental, and spiritual life. **Objective:** The objective of this study is to assess the current scientific evidence related to the adaptation and coping process experienced by people who have survived neurological surgery due to brain tumor. **Methods:** A systematic search of the scientific evidence published in English and Spanish was carried out from 2009 to 2017 in databases such as PubMed, Scielo, and Google Scholar, using the keywords "adaptation", "coping", "Roy's model", "brain tumor", and "surgery". The inclusion criteria were set forth according to the questions raised. From a total of 75 articles found, 15 were selected; those that met the inclusion criteria. **Results:** The systematic reviews, quasi-experimental, qualitative narrative and descriptive, present evidence of cognitive deterioration, deterioration of quality of life, anxiety, physical limitations and stress, in some instances in the long term regarding survivors of brain tumor such as meningiomas and gliomas. One intervention study that used the adaptation and coping model, regarding improvement of quality of life, is reported. **Conclusions:** The literature shows diverse forms of adaptation and coping to everyday life after surgery, also showing physical and psychological complications. It is suggested to carry out studies that inform about nursing interventions necessary to provide holistic care, based on the experiences of people who go through these experiences.

Palabras clave: Brain neoplasms; adaptation; coping (DeCS, BIREME).

¹Universidad de Guanajuato, Celaya-Salvatierra Campus, Division of Health Sciences and Engineering, PhD program in Nursing Sciences. Email: cf.meza@ugto.mx

²Universidad de Guanajuato, León Campus, Division of Health Sciences, Nursing and Obstetrics Department, León Main Office. Guanajuato, Mexico.

³Universidad de Guanajuato, Celaya-Salvatierra Campus, Division of Health Sciences and Engineering, Clinic Nursing Department, Guanajuato, Mexico.

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* Corresponding author

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INTRODUCTION

Hundreds of millions of people around the world suffer from neurological disorders; more than 6 million people die every year due to strokes, and more than 80% occur in low and middle income countries⁽¹⁾. Brain tumors represent 2% of all neoplasms, which include from well-differentiated and relatively benign injuries such as the hemangiomas, to highly invasive and differentiated injuries such as the glioblastoma multiforme^(2,3). Global incidence rate of primary tumors (due to their origin) of the central nervous system (CNS) is 10.82 per 100,000 persons a year⁽²⁾. In developed countries only 14% of patients diagnosed with tumors in the CNS survive more than 10 years, and only 1% is preventable⁽⁴⁾.

In her model, Callista Roy describes four adaptation modes regarding the behavior of people toward the illness: physiologic, interdependence, role function, and self-concept. This is focused on determining the level of adaptation as integrated, compensatory, or compromised. For her, the adaptation is a process by means of which thoughts and feelings choose conscious awareness to create an individual human integrity^(5,6). Therefore, it is necessary to familiarize with the complex process of adaptation, which includes physiological, psychological, and social integration of the people. The objective of this literature review is to know how a person subject to a neurological surgery adapts to, and copes with, everyday life.

METHODOLOGY

Before searching for articles, some questions were developed, such as: How is the adaptation and coping process of the patient who had brain tumor surgery? Which is the adaptation process of patients with brain tumor who had brain surgery according to the Roy model? How do the adaptation process, mode, and self-concept occur in people with brain tumor who survived surgery?

Search Strategies

A search in databases such as PubMed, Scielo, and Google Scholar took place.

First search using Boolean operators and key words: Roy Model and adaptation and brain, not children, not pediatric, not digital, in the years 2009 to 2017. With a total of 20 chosen articles, 8 of which included the inclusion criteria, only 6 reading, and that contributed to the literature review.

In the second search, key words with Boolean operators were coping and adaptation, brain tumor, in the years 2014 to 2017, with a total of 49 articles. When using the filter using the words not pediatric, not caregiver, and not digital, 7 articles left for review.

In the third search, key words and Boolean operators were coping, adaptation, brain tumor, not pediatric, not caregiver, not digital, not acoustic, year 2017, with a total of 6

articles included, two of which were chosen for the literature review. There were a total of 15 articles.

Description of the articles

Of the 75 articles found, only 15 were included according to the inclusion criteria, first question, database, and key words. The type of study of these articles was descriptive/observational analytical ($n= 6$), systematic review ($n= 3$), quasi-experimental ($n= 1$), qualitative ($n= 3$), experimental ($n= 1$). In 14 articles, the language was English; only one was in Turkish. The origin of the article was the Netherlands ($n= 4$), Turkey ($n= 4$), USA ($n= 3$), Australia ($n= 1$), England ($n= 1$), Germany ($n= 1$), and China ($n= 1$). The year of the articles ranges according to the search, from 2014 to 2017 with 11 articles, and 4 articles from 2009 to 2013.

RESULTS

According to the quasi-experimental revised study, Baksi and Dicle⁽⁷⁾, in a comparative study of 95 patients (control $n= 50$; experimental $n= 45$), the impact of an educational intervention based on the Roy model with better copying of stress in patients with brain tumor within the experimental group was found ($p= 0.05$).

The experimental study was mainly included because Aramesh et al.⁽⁸⁾, report that the Roy Adaptation Model used to assess the consequences of patients with neurologic trauma is better than the ESI index.

Regarding systematic reviews, the one from Ownsworth et al.⁽⁹⁾ is mentioned, who report that only 10 of 17 studies in total show the impact on psychotherapy, the support based on the family, the cognitive rehabilitation, and the interventions based on the activities related to self-concept of people with traumatic brain injuries; they conclude that loss of independence, loss of self-confidence, and loss of relationships are mentioned. Depending on the individuals, the information was useful to acknowledge their experience and to identify the need of more psychological services for people who present a brain tumor. Likewise, they found there is improvement in the self-concept with the pre-and-post groups when patients with brain lesion went through a rehabilitation intervention. In another systematic review about cognitive functioning in patients with meningioma, Meskal et al.⁽¹⁰⁾ included 11 articles, concluding that people with meningiomas already present cognitive deterioration before the surgery (memory, attention, and executive functions); cognitive function slightly improves after the surgery. General results are inconsistent regarding the cognitive functioning before the surgery and subsequent improvement.

Zmanipoor Najafbadi⁽¹¹⁾, in a systematic review, report 19 articles and concludes that the quality of life in people with meningioma is lower than the quality of life of healthy controls. Although patients with meningioma had a better quality of life than patient with glioma, this difference was

not clinically relevant. Although resection of the tumor improves the quality of life, this is persistently low at long-term, compared with that of the healthy controls.

In the qualitative studies, Simsek y Dicle⁽¹²⁾ examined the adaptation modes of the patient with primary brain tumor according to the Roy Adaptation Model, carrying out a semi-structured interview to 17 people. The categories found in the physiological mode were: drugs side effects, exposure to daily life activities, fatigue, headache, visual impairment, and neurological problems; in the self-concept mode, they described stress caused due to a feeling of discomfort as a result of an uncertain future; in the role function mode, the problems are related because they cannot meet the gender role, and the exposure to have other relationships. Likewise, Wenström et al.⁽¹³⁾, in a narrative qualitative study described the experiences of women after the meningioma surgery and its meaning; the categories found were felt as a double threat, that is, tumor and surgery; the benign tumor as threatening and the surgery as curative and risky; the injury as an open door; the suffering body that exceeds life; women who could not recover their body; sense of fragility; and hypersensitivity to impression. Lucas⁽¹⁴⁾, for his part, in 2010 published the qualitative analysis of the interviews performed to hundreds of patients who were cared for in his onco-neurology clinic, resulting three main subjects: loss of independence (physical and financial), loss of self-confidence (sense of humor, personality), and loss of relationships (friends, work, family).

Within the analytical observational studies, Waagemans et al.⁽¹⁵⁾ included 89 patients with meningioma and they measured the long-term impact of the cognitive deficit and epilepsy on the quality of life. No differences are reported with healthy controls in 7 of the 8 scales of the Quality of Life instrument, the SF36; the only difference was that patients with meningioma reported more limitations due to physical problems ($p < 0.5$). Additionally, Habets et al.⁽¹⁶⁾ measured the impact of the cognitive damage in 62 patients with high grade glioma in the proper functioning of daily life, obtaining that 79% of them already had a cognitive damage before the surgery, in at least one domain. After the surgery, they studied 39 patients finding that 59% had cognitive damage. During follow-up, 49% showed improvement, while 23% worsen.

Likewise, Wolters Gregorio⁽¹⁷⁾ discussed the relationship between executive functioning, coping, depressive symptoms, and quality of life in people with neuropsychiatric symptoms with acquired brain damage. He reports that people with executive dysfunction were those with passive coping style ($\beta = .37, p < .01$), and this is in turn related to lower quality of life ($\beta = -.57, p < .001$) and higher number of depressive symptoms ($\beta = .65, p < .001$). Moreover, those patients with a coping style focused on the problem, had a better executive functioning ($\beta = -.94, p < .05$). In the same vein, the study carried out in China, by Bao et al.⁽¹⁸⁾ where a prevalence of 42.8% of anxiety and 32.4% of depression were reported in 222 patients with tumors

of the central nervous system who were interviewed and propose the implementation of interventions to promote hope and optimism based on the specific needs of the patients. Accordingly, Holmes et al.⁽¹⁹⁾ have demonstrated that psychological challenges of patients with tumors of the central nervous system (adaptation, mental difficulties, grief, uncertainty, etc.) require a psychiatrist to improve patient management and communication with the health team.

Lin Lin⁽²⁰⁾, in a study from 2014 carried out with 186 patients with primary brain tumor in different stages of illness, mentioned that the uncertainty level of the patients with active treatment was as high as the one shown by those who were recently diagnosed. The highest uncertainty predictor was changes in status of employment related with the illness. This indicates the need patients have to acquire coping skills to manage uncertainty.

Additionally, Krupp et al.⁽²¹⁾ in a retrospective study in patients 15 months (± 3.6) after a supratentorial meningioma surgery, found a negative correlation between age and cognitive performance ($p < 0.001$). Seventy three (73%) percent of the younger patients stated they are not satisfied with their lives; 68% stated their inability to accept the illness. Also, single patients showed depressive copying with more ($p < 0.05$) and lower satisfaction with life ($p < 0.05$).

The aforementioned articles, showed in the table, are presented in search order.

DISCUSSION

Based on the questions asked: How is the adaptation and coping process of patients who had brain tumor surgery? And, which is the adaptation mode of patients with brain tumor who had brain surgery?

Several categories related to the copying and adaptation process of people who had brain tumor surgery and how they were evaluated by the authors were found.

The first one was quality of life. It was found in this literature review that quality of life is lower in people with meningioma than healthy controls, even after the resection; additionally, although patients with meningioma had a better quality of life than those with glioma, this difference was not clinically relevant⁽¹¹⁾. In different functioning and association among executive, psychosocial, and copying functioning low quality of life is reported after acquiring the brain damage. Passive copying is implied in patients with brain tumors, as well as epilepsy, at long-term, thus, the quality of life is affected at long-term⁽¹⁵⁾.

Anxiety and depression. A study reports a prevalence of 42.8% of anxiety and 32.4% of depression in 222 patients with con tumors of the central nervous system interviewed. Pearson correlation showed that anxiety was related to hope ($p < 0.01$), optimism ($p < 0.01$), and general self-efficacy ($p < 0.01$)⁽¹⁸⁾. After the surgery, single patients had a higher frequency of depressive copying ($p < 0.05$) and lower satisfaction with life ($p < 0.05$)⁽²¹⁾.

Cognitive deterioration. There is cognitive

Table 1. Characteristics of the articles chosen in this literature review

Title, authors, and country	Journal and year	Type of Study	Sample	Instrument	Results
Impaired quality of life related to the health in the meningioma: Systematic review. Zmanipoor, A., et. al. Netherlands..	Neuro-oncology 2016.	Systematic review.	19 articles met inclusion criteria.	Systematic search: Key words: Meningioma, Calidad de vida (quality of life).	Patients with meningioma have better quality of life than patients with glioma, although this difference was not clinically significant ⁽¹¹⁾ .
Cognitive functioning in patients with meningioma: Systematic review. Meskal, I., Gehring, K., Rutten, G., SitsKoorn M. Netherlands.	J Neuro-Oncology 2016.	Systematic review.	11 articles were included within inclusion criteria.	Electronic database: Pubmed	Although people with meningiomas show cognitive deterioration before the surgery (memory, attention, executive functions), this situation slightly improves after the surgery. There is no consistency among the results of the studies ⁽¹⁰⁾ ..
Long-term impact of cognitive deficit and epilepsy in the quality of life in a patient with meningioma. Waagemans, M. y cols. Netherlands.	Neuro-surgery-online. 2011	Analytical observational.	89 patients.	Neuropsychological test battery	Patients with meningiomas do not differ of healthy controls in 7 of 8 SF36 scales; the only difference was that patients reported more limitation due to physical problems ($p < 0.5$) ⁽¹⁵⁾ .
Revision of states of adaptation of patients with primary brain tumor according to Roy Adaptation Model: A qualitative analysis. Simsek, A., Dicle, A. Turkey.	Journal of Neurological Sciences .	Qualitative.	17 patients.	In-depth interview. Semi-structured interview.	Drugs side effects. Influences in daily life activities. Fatigue, headache, visual impairment, neurological impairment. Role function: gender role. Self-concept function: feeling of discomfort and uncertainty about the future ⁽¹²⁾ .
Living a paradox: Experience of women after a meningioma surgery. Wenström, I, Eriksson, LE. Ebbeskog, B. England.	Journal of advanced nursing, 2012.	Qualitative, Narrative.	6 personas	Interview. Observational.	Double threat: tumor and surgery; benign tumor as threatening; the surgery as curative and risky; the injury as an open door; THE suffering body that exceeds life; women who could not recover their body; sense of fragility; and hypersensitivity to impression ⁽¹³⁾ .

<p>Tumor and effects of the surgery in the cognitive functioning in patients con high grade gliomas.</p> <p>Habets, E., Kloet, A., Walchemback, R., Vech, C., Klein, M. and Taphoorn. Netherlands.</p>	Acta Neurochir, 2014.	Cohort analytical observational.	Control: 31. Tracing: 62. Total: 93.	Cognitive Domains Test.	Compared with healthy controls, the cognitive function of patients is significantly lower in all the domains. After a 5-week follow-up after the surgery, 59% of patients had a cognitive dysfunction. Forty nine (49) percent showed improvement, and 23% get worse ⁽¹⁶⁾ .
<p>Psychiatric liaison of the service of tumors of the central nervous system.</p> <p>Holmes, A., Adams, S., Hall, S., Roshental, M. and Drummond, K. Australia.</p>	Neuro-Oncology, 2015.	Descriptive, retrospective.	Analysis of 5 years of problems experienced by the patients and their management by the psychiatrist.	Socio-demographic variables. Type of tumors, psychological challenge, psychiatric diagnosis.	Frequencies and percentages for all variables ⁽¹⁹⁾ .
<p>Association between executive functioning, psychosocial, and copying after acquiring the brain damage.</p> <p>Wolters Gregorio, y cols. Netherlands.</p>	British Journal and Clinic Psychology Society 2015.	Observational correlational.	First sample: 93 Second sample: 58	1.- Stroop color word test. 2.- Frontal systems behavioral scale. 3.- Utrecht Coping List. 4.- Cuestionario de salud del paciente. 5.- Cuestionario de satisfacción de la vida.	The executive dysfunction is associated with more use of coping ($p=0,01$). Passive coping is associated to a lower quality of life ($p= 0,001$) and depressive symptoms ($p=0,001$) ⁽¹⁷⁾ .
<p>Prevalence and positive psychological variables associated with anxiety and depression among patients with tumor in the central nervous system in China</p> <p>Bao, Y., et al. China.</p>	Psycho-Oncology 2017	Analytical observational.	N=222 personas.	1.- Anxiety and Depression Scale. 2.- Herth and Hope Index. 3.- Orientation Scale, Revised. 4.- General Self-Efficacy Scale. 5.- Demographics and clinical symptoms wsith tumors of the SNC.	Education had a significant effect in the scores of anxiety ($p=0,005$) and depression ($p=0,001$). Pearson correlation showed that anxiety was negatively related to hope ($r=0,46$, $p<0,01$), optimism ($r = 0,39$, $p<0,01$) and general self-efficacy ($r=0,21$, $p<0,01$) ⁽¹⁸⁾ .
<p>Significant uncertainty predictors in patients with brain tumors.</p> <p>Lin, L., Chien, L., Acquaye, A., Vera, E., Gilbert, M., Armstrong, T. EUA</p>	J Neuroncolgy. 2015	Descriptive, observational	N= 186 pacientes.	1.- Mishel Uncertainty in Illness Scale. 2.- Demographic Information Sheet. 3.- Clinical Assessment Tool.	Predictors in total, three subscales (ambiguity, incoherence, unpredictability, and other triggering factors) were different among the treatment groups ($p=0,01$) ⁽²⁰⁾ .

Effect of one intervention using the Roy Model in patients with brain tumors in symptoms and adaptation to stress. Baksi A., Dicle, A. Turkey.	International Journal of Caring Science, 2017.	Intervention: Quasi-experimental	95 patients Control Experimental	1.- Karnofsky performance status. 2.- MD Anderson Symptom inventory-brain tumor Turkish. 3.- Ways of Coping with Stress Scale.	There is significant difference among the control group and the experimental group, considering the statistics value ($p=0,05$) ⁽⁷⁾ .
Psychosocial implications with the patient with high degree glioma. Michel R. Lucas. EUA.	Journal of Neuroscience Nursing, 2010.	Qualitative, experiences.	A 7 year period, from 2001 to 2008.	Semi-structured interview.	Three categories: loss of independence, loss of self-confidence, and loss of relationships ⁽¹⁴⁾ .
Impact of the rehabilitation in the self-concept, traumatic brain damage: an exploratory systematic review of the methodology, intervention, and efficiency. Ownsworth, T. and Haslam, C. Australia.	Neuropsychological Rehabilitation. 2014.	Systematic review.	17 studies in the database.	Key words.	Only 10 articles found improvement in the self-concept with pre and post groups ⁽⁹⁾ .
Comparing the efficiency of the nursing care base don ESI, Triage and Roy Adaptation Model to predict the need of an UCI or admission room among patients with head trauma. Aramesh Z., Mazloun R., Aghebati N. and Masshadi Nejad, H. Turkey.	Journal of Manzanaran University of Medical Science. 2017.	Experimental	400 people, 200 in each group.	ESI (Emergency severity index) Triage. Roy Model	Comparing with the ESI Index, Roy Adaptation Model, could result in less mistakes to predict the consequences of patients with neurological trauma ⁽⁸⁾
Assessment of neuropsychological parameters, quality of life, to assess the results with patients with supratentorial meningioma, surgically treated. Krupp W. et al. Germany	Neurosurgery. 2009.	Analytical observational	91 Patients	1.-Test of Attention. 2.- LPS Intelligence Test. 3.- Freiburg Questionnaire of Coping with Illness.	There is negative significance of correlation among the age of the patient and the cognitive performance ($p=0,001$). Single patients show more frequency of depression ($p=0,05$) ⁽²¹⁾ .

Source: Own elaboration

n = 16

deterioration in different brain tumors, even before the surgery; however, general results are inconsistent regarding the cognitive functioning before the surgery and subsequent improvement⁽¹⁰⁾. Cognitive deterioration has been reported in people with brain tumors, even before the surgery. However, the general results are inconsistent due to the different designs of research and instruments used to measure the cognitive deterioration as well as the location of the brain tumor, and the presence of epilepsy. In his intervention, Lin reports uncertainty in patients with brain tumors such as ambiguity, incoherence, unpredictability, and other triggers which were different among the treatment groups ($p=0.01$)⁽²⁰⁾. Other authors mentioned that 79% of the people with glioma already have a cognitive damage before the surgery except in one domain. After the surgery, 39 patients were studied, and it was found that 59% had cognitive damage. In the follow-up, 49% showed improvement while 23 % got worse⁽¹⁶⁾.

Physical problems. In a study of people with meningiomas in the Netherlands in 2011, they did not differ from healthy controls in 7 out of 8 SF36 scales; the only difference was that the patients reported more limitations due to physical problems ($p<0.5$)⁽¹⁵⁾.

Various neurological consequences. The categories in qualitative studies were drugs side effects, exposure to daily life activities, fatigue, headache, visual impairment, and neurological problems⁽¹²⁾. The adaptation, mental problems, grief, and uncertainty, among others, occur in patients with tumors in the central nervous system requiring of a psychiatrist to improve patient management⁽¹⁹⁾.

Perceptions and meanings. In the narration, patients have described the benign tumor as threatening, and the surgery and curative and risky. The injury as an open door; the suffering body that exceeds life; women who could not recover their body; sense of fragility; and hypersensitivity to impression⁽¹³⁾. Other psychosocial implications: loss of Independence, loss of self-confidence, and loss of relationships⁽¹⁴⁾.

Which is the adaptation process of patients with brain tumor who had a brain surgery according to the Roy model? How does the adaptation process, mode, self-concept occur in people with brain tumor who survive surgery?

Only one of the articles seems to respond to these questions, and that is that it appears that non adaptive behavior that experience people with primary brain tumors include:⁽¹²⁾

Physiological mode: Drugs side effects, exposure to daily life activities, fatigue, headache, visual impairment, and neurological problems.

Self-Concept Mode: Stress caused due to a feeling of discomfort and uncertainty about the future.

Role function mode: Do not be able to meet the gender role, and the possibility of being abandoned or deceived.

Interdependency Mode: The deterioration of social relationships caused by the negative conditions, which are experienced in the other two modes, makes they are isolated and alone, without partner, friends, work, or family.

CONCLUSION

In order to address the care of brain tumor surviving patients, it is necessary to know their copying and adaptation process, inquire about their quality of life, presence of depression, anxiety, cognitive deterioration, level of uncertainty, etc., both at the short and at the long term. It is possible that this process may be different depending on the type of tumor they had, which ranges from glioma, astrocytoma or meningioma, and the type of surgery. Assess what other factors before the surgery may influence the copying process in order to rejoin later, such as quality of life, stress, psychological support, and physical, neurological, and cognitive functions. The realization of studies about the experiences of people who went through these situations. It is necessary to inquire about interventions that improve the coping process in the life of people who survived brain tumor surgery, concerning psychological, biological, social, spiritual, and environmental aspects.

CONFLICT OF INTEREST

The authors declare they do not have any conflict of interest.

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